

TECHNICAL ASSISTANCE REPORT  
FOR THE  
ACCESS TO RECOVERY GRANT PROGRAM  
SETTING UP A SYSTEM FOR CLIENT FOLLOW-UP  
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## 1. Introduction

During the summer of 2007, the Center for Substance Abuse Treatment in the Substance Abuse and Mental Health Services Administration, (SAMHSA/CSAT) tasked its Access to Recovery (ATR) technical assistance contract, the Performance Management Technical Assistance Coordinating Center (PM TACC), to develop a set of resource materials for incoming second-round ATR grantees. The PM TACC prime contractor, the American Institutes for Research (AIR), and their subcontractor, JBS International, Inc., brought to this product-development task the experiential knowledge rooted in service to CSAT and the ATR Round 1 grantees throughout all phases of the first-round grants-- from the pre-application roll-out of the Presidential initiative, to early implementation and sustained operation of the grant programs, to their eventual close-out. SAMHSA/CSAT's selected topics for the resource materials target key issues, barriers, challenges, and decision points that faced the first-round grantees during each of these phases. They are written from the PM TACC contract's experiences with the 15 grantees that broke new ground for the substance abuse field by demonstrating the feasibility of using a voucher model for providing publicly-funded treatment and recovery services.

Some of the newly developed resource materials modify, update, and consolidate technical assistance (TA) reports emanating from the Round 1 grantees' TA experiences. Other products provide syntheses of the Round 1 grantees' experiences related to various topics central to effective and efficient planning, implementation and management of an ATR grant. CSAT has requested that these reports be made available to Round 2 ATR grantees so that the new cohort may benefit from the experience and work accomplished by the initial ATR grant recipients. Below are lists of the available reports.

### SYNTHESES

- Access to Recovery Report: Lessons Learned from Round 1 Grantees' Implementation Experiences
- Administrative Management Models: Compilation of Approaches by Initial Access to Recovery Grantees
- Planning and Implementing a Voucher System for Substance Abuse Treatment and Recovery Support Services: *A Start-Up Guide*
- Setting Up a System for Client Follow-Up
- Recovery Support Services
- Case Management
- Summary and Analysis of Grantee Fraud, Waste, and Abuse Activities

### TA CONSOLIDATED REPORTS

- Basics of Forecasting and Managing Access to Recovery Program Expenditures
- Compilation of Technical Assistance Reports on Rate Setting Procedures
- Development of a Paper-based Backup Voucher System
- Financial Management Tools and Options for Managing Expenditures in a Voucher-Based System: Round 1 Grantee Experiences
- Motivational Interviewing: A Counseling Approach for Enhancing Client Engagement, Motivation, and Change

- Outreach to Faith-Based Organizations: Strategic Planning and Implementation
- Strategies for Marketing Access to Recovery to Faith-Based Organizations
- Targeted Populations: Technical Assistance Examples

## **About this TA Report**

One way for programs to determine the extent to which they are achieving their goals and to examine client outcomes is to collect goals-specific data during client intake and again at specified follow-up points. This enables programs to examine how client behaviors have changed over time and to determine whether midcourse corrections are needed to improve or increase client services. Conducting this type of data collection may also allow programs to examine client outcomes to determine any differences between providers in their program networks. While CSAT requires ATR grantees to collect Government Performance and Results Act (GPRA) data at three data points: intake, discharge, and 6 months post intake, programs may choose to collect additional data at similar or additional collection points.

Because the ATR programs are designed to serve a high volume of clients utilizing services and resources from multiple providers, creating a system for coordinating, overseeing, and monitoring data collection is essential. This document, *Setting Up a System for Client Follow-Up*, is intended to provide guidance about putting in place a system for collecting follow-up data from clients who receive ATR services. The document includes elements that are considered to be keys to a successful follow-up system, regardless of the size or scope of the program/provider, and identifies decision points where programs should consider how best to customize the systems and protocols for their programs.

If, after reviewing this document, you determine that your program requires further assistance to set up your follow-up system, you may request technical assistance from CSAT. The most common comment made by grantees that have received technical assistance for follow-up is that they wish they had received the assistance earlier.

## **About the ATR Program**

ATR is a competitive discretionary grant program funded by SAMHSA that provides vouchers to clients for purchase of substance abuse clinical treatment and Recovery Support Services (RSS). ATR program goals include expanding capacity, supporting client choice, and increasing the array of faith-based and community-based providers for clinical treatment and recovery support services. Key among ATR's goals is providing clients with a choice among qualified providers of clinical treatment and RSS. Under the ATR program, treatment and RSS can be provided by both nonsectarian and faith-based organizations (FBOs).

## 2. The Importance of Good Follow-Up

### Response Rates

While anecdotal evidence about the successes of your program may provide interesting context within which to discuss your program outcomes, funders, stakeholders, and the public may be more interested in learning about your program's general outcomes. In order to examine program outcomes that can be generalized to the population served by your ATR program, you will need to obtain high response rates for your follow-up data collection. Follow-up attrition can severely bias the conclusions about your program (Graham & Donaldson, 1993; Gray, Campanelli, Deepchand, & Prescott-Clarke, 1996). Additionally, CSAT has set an 80% minimum response rate for GPRA follow-up data collection, and the follow-up system that you set up can assist your program in meeting that requirement.

By considering some of the reasons for low follow-up rates, it is easy to imagine how low response rates might bias the observed outcomes of a study. This is especially true when we consider that addiction is often cyclical in nature, including times of treatment, abstinence, and relapse (Carroll, Power, Bryant, & Rounsaville, 1993; Stout, Rubin, Zwick, Zywiak, & Bellino, 1999). A program may have the easiest time finding clients that are still in the program at the point of follow-up and/or clients that have recently, successfully graduated from their treatment program. Conversely, a program that serves criminal justice populations may be able to most easily find clients that have returned to jail or prison. If only these easiest-to-find clients are included in a follow-up sample, the picture of program outcomes may be artificially positive or artificially negative.

A program cannot build evidence-based practices by including follow-up information from only those clients who are doing well at the point of follow-up. Conversely, a program cannot articulate its successes by only following up on those clients that have relapsed or receded. It is important to include a large enough sample, including a cross-section of clientele in order to truly monitor program effectiveness.

### What Can You Learn From Collecting Follow-Up Data?

By following up with your clients, you can examine the overall outcomes of your program—how the ATR program is doing across all providers and service types. You can also examine how individual providers are performing, how outcomes differ for different types of clients or services provided, and how outcomes differ for clients in different regions served by your ATR program.

### ***Overall Program Outcomes***

Understanding the overall outcomes of your program can help you to learn about what contributes to your clients' success, as well as identifying needs for program improvement. You can examine the interventions being used by your program and the outcomes of your client population to make decisions about how to allocate your resources by identifying the most effective interventions and services and to strengthen existing services. You can improve your

program by determining what services should be expanded, reduced, or modified while also examining the extent to which your program is meeting its goals.

Follow-up data collection can help to support long- and short-range program planning by allowing you to examine the outcomes of your program activities. This type of examination can help you to determine what activities require more or less staffing and increased or decreased budgeting.

The best way to convince the public, your funders, and your shareholders that your ATR program should be maintained or expanded is by demonstrating and articulating that your program is making a difference. A well-thought-out and well-executed evaluation of your program's outcomes will help you to do this. An important component of any evaluation is the follow-up data that must be collected to measure outcomes.

### ***Individual Provider Differences***

Collecting client follow-up data can assist your program in monitoring the performance of the providers in your service network. This will allow your program to target training needs, direct individual provider improvements, and determine the types of providers that most benefit your client populations. While these types of outcomes analyses can assist the program in planning their budget, staff, and provider allocations, they can also help the program to assist clients in a more immediate fashion. For example, programs can make service adjustments when the outcome data shows a high relapse rate.

An important aspect of the ATR program is client choice. That is, clients must be able to make their own choices about the providers from whom they will receive services. By examining how different types of clients benefit from different providers and/or services in your ATR network, your program can provide informed assistance to clients when they are making choices about which providers or services to choose.

### 3. Planning for Follow-Up

There are some important considerations to be taken into account when planning your program's follow-up strategies and laying out your protocol. This is particularly true for programs that have decentralized components. This chapter discusses some of the factors that will need to be considered when planning for follow-up, such as the following:

- When to start
- Funding
- Who will do it
- Response rates
- Protocols and forms
- Monitoring

For reference, attached at appendix C is a list of articles from the literature on tracking methods.

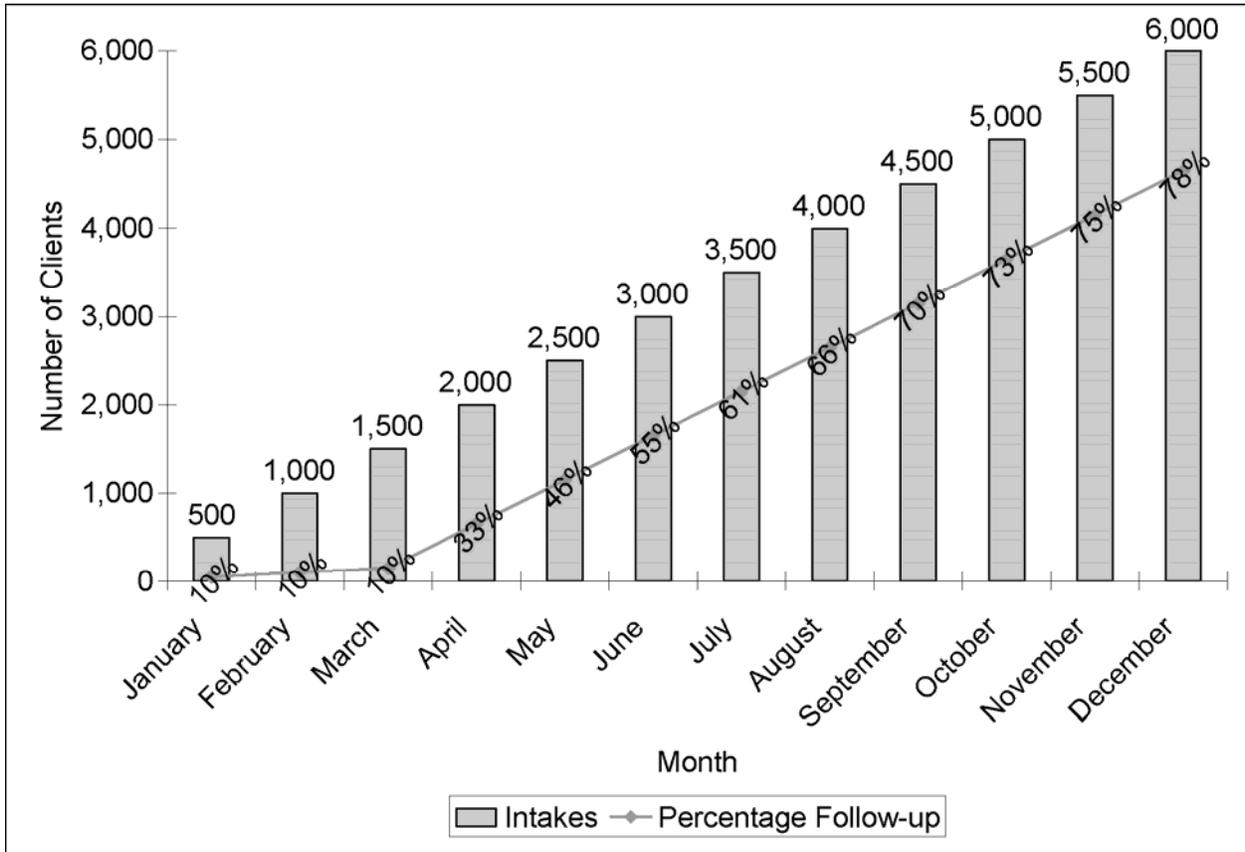
#### How Important Is It to Set up Your System Early?

One aspect of the ATR program is the high volume of clients that may require follow-up, which creates an urgency for training and system setup. Falling behind on follow-up data collection for any amount of time may create a situation in which programs are unable to catch up because service provision immediately inflates the denominator. Once you begin serving clients, the number of people who become a part of the follow-up data collection pool is immediate. If you don't have a follow-up system in place, with people continually entering the system, you may never be able to achieve an 80% follow-up rate.

**For example:** Suppose a program begins client intakes in January with 500 clients entering the program each month. The program will serve 6,000 clients per year. To maintain an annual follow-up rate of 80%, the program will need to collect follow-up data on 4,800 clients per year. Assume that *without* a follow-up system in place, the program could collect follow-up data on 10% of intakes. How many months can the program go without a follow-up system before it would be impossible for the program to achieve an annual follow-up rate of 80%?

As illustrated in figure 1, if the follow-up system is not put in place by the 3rd month of the program, *even if data is collected for 100% of clients thereafter*, it will be impossible for the program to maintain an 80% annual follow-up rate.

**Figure 1. Client Intakes and Cumulative Follow-Up Rates**



In figure 1, the cumulative follow-up rate for June is 55% ( $10\% + 10\% + 10\% + 100\% + 100\% + 100\% = 330\% / 6$ ). The total number of clients you should have collected follow-up data on would be 2,400 (80% of 3,000). However, in reality you have only collected follow-up data on 1,650 clients ( $1,652 / 3,000 = 55\%$ ).

## Funding for Follow-Up

One important planning aspect is funding the tracking and follow-up activities for your program. There are several funding-related questions that your program will need to address when creating its follow-up protocols and plans. While it is not possible for this document to provide answers to the questions posed, this section is intended to direct your program in thinking through these important funding-related questions, and to begin devising plans around them. The funding and resource questions that your program will need to consider are as follows:

1. What is the level of staffing, client, and collaborator efforts required for collecting the follow-up sample you will need?
2. What kind of staffing is needed
  - a. For creating your follow-up plan?
  - b. For conducting tracking and locating activities?

- c. For oversight for these activities?
- d. For collecting follow-up data?
3. What kinds of funds will be needed
  - a. For provider incentives (if needed)?
  - b. For client incentives?
4. If you don't have the funding that will be required for implementing your plan, what will you do to secure the required funding? Or, are there other options?
5. How will you change your protocol to align with the available resources?
6. Frequent review of the follow-up system is important. You may need to revise your plans from time to time.
  - a. What are the budget considerations when changes are required?
  - b. What are the staffing considerations?
  - c. How much time will be required from the client?
  - d. Are incentives available?
  - e. Will collaborating agencies allow clients to be pulled from activities to complete follow-ups?

Answering these questions will help you to consider the factors required to create a protocol that can operate within the confines of your funding. Your follow-up protocol should be created with any funding limitations in mind.

Research has shown that incentives can increase research and follow-up participation (Hoffman, Burke, Helzlsouer, & Comstock, 1998), even when intrusive or sensitive data is being collected (Kissinger et al., 2000), and specifically with CSAT program clients (Caliber Associates, 1997). CSAT allows its grantees to use CSAT funds of up to \$20 per participant per follow-up for GPRA follow-up participation. If your program determines that other follow-up data collection activities will be performed, you may need to secure other funds to cover incentives for these activities.

There is also an interesting and relatively new body of evidence with regard to subject fee compensation and “contingency management” that has found that neither “magnitude” (e.g., rate of compensation) nor “mode” (e.g., cash or gift cards) had an effect on new drug use or perceptions of coercion for substance abusing clients who are involved in research (Festinger et al., 2005). Moreover, many studies have documented that “contingency management” (providing tangible incentives/prizes) techniques have been effective in motivating individuals battling addictions (e.g., tobacco, alcohol, and other drugs; gambling) to remain abstinent and involved in

treatment and did not increase addictive behaviors (Prendergast, Podus, Finney, Greenwell, & Roll, 2006; Petry, Alessi, et al., 2006; Petry, Kolodner, et al., 2006) These research studies suggest that compensation can benefit research participants and increase follow-up response rates.

## **How to Determine Who Will Conduct Follow-Up**

In a system where there are multiple providers operating under a single program, it must be determined who will be responsible for conducting any follow-up activities. Programs may opt to make follow-up activities the responsibility of program staff (State or organization level). Programs may choose to centralize by hiring contractors to conduct follow-up activities. Finally, programs may opt to have providers bear the responsibility for conducting follow-up activities. Each of these options requires a different set of planning steps and activities.

### ***Program Staff Conducting Follow-Up***

Having program staff conduct follow-up activities will provide a centralized system for follow-up. There are several things to consider when determining whether this type of centralized system will work for your program:

1. How spread out (geographically) is your program?
  - a. If your program covers a large land area, how will centralized staff perform any outreach or in-person activities required for follow-up?
2. Who will be responsible for follow-up?
  - a. How many staff will be needed?
  - b. Is there a need for additional staff, or will existing staff do this work?
  - c. Can your program budget support the staff requirements?
3. Who will be responsible for monitoring progress?
4. How will follow-up staff maintain communication with provider staff?
5. Will follow-up staff be involved with intake?
  - a. If yes:
    - i. What will be the extent of their involvement?
    - ii. Will they conduct intake interviews?
    - iii. Will they collect information necessary for follow-up and tracking?
    - iv. Will they set the follow-up appointments?

- b. If no:
  - i. Who will collect necessary follow-up and tracking information?
  - ii. If follow-up staff will be collecting follow-up and tracking information, at what point will this be done?
  - iii. Who will be responsible for setting follow-up appointments?
  - iv. At what point will follow-up staff be introduced to clients?

### ***Consulting Organization Conducting Follow-Up***

Many of the same questions that your program will need to consider if program staff will be conducting follow-up will also need to be considered if a centralized or consulting entity will be responsible for conducting follow-up. In addition to the questions already posed, your program should consider the following:

1. How will the follow-up organization communicate with the program?
2. Will the program be involved in the communication between the follow-up organization and the providers?
3. Where will the consultant(s) be situated?
  - a. Will there need to be regional, county-based, or city-based follow-up consultants?
4. Who will be responsible for overseeing the follow-up entity?
  - a. What information will be collected from the entity?
  - b. How frequently will information be collected?
  - c. How will feedback be provided, and how often?
  - d. How will benchmarks and standards be measured?
5. Who will be responsible for data management?
6. What steps will be taken if follow-up expectations are not being met?
7. What steps will be taken if follow-up expectations are exceeded?

### ***Providers Conducting Follow-Up***

Service providers within each ATR program's network may provide many types of services, including treatment, recovery support, and ancillary services. The service intensity provided by different providers may vary among clients. Additionally, some providers may be more familiar and/or experienced with data collection than others. Therefore, if ATR programs decide to have

providers collect their follow-up data, they will need to determine which providers will be most logical and capable of doing the job. In addition, there is information that must be collected from the clients at intake and shared with the providers to facilitate tracking and follow-up.

It should be noted that for some, most, or even all clients the follow-up data collection point may extend beyond their period of service. In these cases, client follow-up will occur when the client is no longer associated with a particular provider. Decisions regarding responsibility for following up with such clients will need to be made early, and staffing, contracting, or provider agreements will need to be put into place.

Regardless of whether clients are still receiving provider services at the follow-up data collection point, close coordination between all service providers, providers who will be conducting follow-up, and the ATR program will be essential. Tracking is facilitated when providers responsible for conducting follow-up know whether clients are still actively involved with other providers. Providers will need to communicate their follow-up progress with the ATR program. The ATR program will need to devise a system for informing and reminding these providers when follow-up data collection points occur. Additionally, it must be determined who will be responsible for keeping track of clients (for example, collecting, reviewing, confirming, and updating locator information), and how locator information will be made accessible to providers.

There are several things to consider when determining whether service providers should collect your follow-up data:

1. How many service providers will be responsible for conducting follow-up?
  - a. What kind of training and retraining will providers receive?
  - b. Who will provide follow-up training?
2. How will responsibility for each client be determined?
3. At what point will providers become responsible for client tracking?
  - a. If they will be involved in tracking and locating:
    - i. When will they receive client locator information?
    - ii. When will they be expected to begin locating activities?
    - iii. What tracking activities will they be responsible for?
    - iv. What level of effort is expected for these activities?
    - v. How will the ATR program monitor tracking and locating activities?
  - b. If they will only be involved in actual data collection:
    - i. Who will be responsible for tracking and locating clients?

- ii. Who will be responsible for setting follow-up appointments, and how will schedules be coordinated?
    - iii. How will providers be given updates regarding client location?
  4. Who will be responsible for data management?
  5. Will there be provider incentives for conducting follow-up activities?
    - a. If yes, what will they be? And how will they be managed (receipts, check requests)?
    - b. If no, how will providers be motivated to conduct follow-up?
  6. How will the ATR program monitor provider follow-up activities?
    - a. What information will be collected, and at what frequency?
    - b. What steps will be taken if follow-up expectations are not being met?

## **Standardizing Follow-Up Activities**

For the data that you collect to be comparable across program participants, you must establish timeframes for data collection. For example, if you want to determine how well your program is doing in promoting abstinence from drug use, you will have to first establish baseline measures for your population by collecting pretreatment or preservice data. You will also have to determine what timeframe you would like to examine by determining posttreatment or postservice data points. These should be established at the outset and be standard for all clients.

One of the most pervasive problems that occurs is the gap between the follow-up and the clinical aspects of the program. It is important for there to be an interface between the follow-up activities and the clinical activities. It is everyone's job and responsibility to ensure that follow-up happens. This should be stated in the memorandum of understanding (MOU). An MOU is a document that spells out each collaborating agencies requirements and responsibilities. The MOU should state that all partners will adhere to the same stringent confidentiality requirements outlined in 42 Code of Federal Regulations (CFR), Part 2. In some models, the funding entity has a requirement for a particular follow-up rate to be upheld. In these cases, the MOU should state the consequences for not upholding the follow-up rates.

You will also need to standardize a process for informing clients about the follow-up activities as well as obtaining consent from clients for locating and accessing clients from other agencies or organizations from which they may be receiving services (Scott, 2004). Data or information that can be used to locate your clients for follow-up must be collected, and it is important for this information collection to be standardized—particularly if multiple providers or entities will be involved in tracking and locating clients for follow-up. Any information collected for locating purposes must be verified, and standard procedures for maintaining contact with clients must be put into place. A protocol for confirming client appointments for follow-up data collection should be created and shared across providers or entities. There also should be a system in place for monitoring this tracking and locating process for all clients.

## **4. Creating Protocols and Forms**

There are a number of protocols, forms, and documents that your program can use to facilitate conducting follow-up activities. These documents should be created during the planning phase of your program. Programs that serve multiple populations may need to create customized forms and documents specifically for use with each population served. Staff that will be involved with conducting any follow-up activities should receive training on activities and use of forms, documentation, and protocols. In the beginning, there must be a policy and strategy for conducting follow-up. This strategy (protocol) should be disseminated to all those who will be involved in the tracking and follow-up activities. Appendix A provides a matrix for programs to use to detail the lines of responsibility for each of the follow-up activities described in this document.

### **Approval to Access and Locate**

As your clients move through their treatment and recovery, they may also move in and out of other institutional services. For example, if you are working with a criminal justice population, there is a chance that some of your clients will return to the criminal justice system during the period in which you will be tracking, locating, and following up with them. It is important to know the requirements regarding contact, information sharing, and disclosure of any agencies or institutions with which your clients may be involved (Scott, 2004; Scott, Sonis, Creamer, & Dennis, 2006). Some agencies or institutions may require Institutional Review Board (IRB) or other types of ethical review boards' approval prior to approving client access. Other agencies may have other required procedures that must be followed or have agency-specific releases that must be completed in order to gain access to, or information about, your clients. By analyzing the characteristics of your client population, your program can determine what agencies and organizations your clients are likely to engage with, and begin researching what procedures and requirements will be necessary for accessing and locating your clients within those agencies and organizations. Some types of agencies and organizations to consider might be as follows:

- Other substance abuse treatment agencies
- Mental health providers
- Educational institutions
- Justice systems (juvenile/adult) (county, State, Federal)
- Medical facilities
- Child welfare systems
- Housing (homeless shelters)
- Faith-based organizations

## Follow-Up Recruitment Script

Your clients have come to your ATR program to receive treatment and/or recovery support services. As part of your program, you may be required or compelled by your funding agency or the State or other organizations that may provide support or oversight of your program to conduct data collection with the clients that participate in your program. This is something your clients are not likely to understand when they come into the program, so this aspect of the program function must be discussed with clients. To ensure that the clients fully understand the data collection and follow-up procedures in which your program would like for them to participate, and that every client is invited to participate in the same way, your program should create a script for recruiting clients for follow-up study.

The purpose of recruiting the clients into follow-up is to engage, motivate, and inform them about the follow-up. This is one component that is grossly underestimated in terms of its impact. If the clients understand the requirements, see the value in them, and can see what is in it for them, they will be more likely to participate. It is important to create a recruitment script that is informative and convincing. Moreover, in the absence of a script, staff may skip important elements that should be communicated to clients. Through developing a script and practicing its delivery, clients can be informed of the following information:

1. The purpose of the evaluation
2. That they will be asked to participate in data collection
3. At what frequency data will be collected
4. When the data collection points will be
5. Who will be contacting the client to prepare for data collection
6. Who will be conducting the data collection
7. What the client will receive for participation (incentives)
8. What the benefits are for them and how their contribution will help others in need of treatment/recovery services
9. How data are protected (confidentiality, exceptions to confidentiality)

**Remember:** The goal of recruitment is to educate and motivate clients to participate in your program's follow-up data collection. Therefore, the recruitment script should make the client feel interested in participating. Outline the benefits that the client will receive through his or her participation (for example: contact, incentives, program improvement).

## Consent Forms

Although your program may have consents for treatment or service provision in place, many programs forget to collect consents to locate clients for follow-up. That means that even if

thorough locator information is collected, the program will be unable to use that information to find the client. If there is an individual named on the locator form that the client hasn't given permission to contact, it limits your ability to keep track of and maintain contacts with the client. If you don't have the appropriate consents in place for providers to tell you the whereabouts of the clients, they won't even tell you if the client is housed or receiving services there; this clearly limits what you are able to do and how well you are able to track and locate the client. Obtaining client consent for follow-up is a crucial step in the process. According to Scott (2004), the follow-up consent form should address the following:

1. Permission for follow-up staff to contact individuals and agencies listed on the locator form to gain information about client whereabouts
2. Permission for individuals or agencies listed on the locator form to provide location information to the follow-up staff
3. Indication that follow-up staff will not disclose the nature of the study

Be sure to include all of the systems of aid that the client may be working with on your consent-to-locate form, so that you have permission from the client to contact these other entities. Also, indicate who will be contacting the client for the 6-month interview, and that these individuals may be in contact with the client's contacts to gain information to locate him or her for follow-up. If you create a consent form specifically for follow-up and locating, you might be able to use a single consent for this purpose that acts as an umbrella consent for all agencies under the ATR program umbrella. This allows you to minimize the frequency of having to collect consent for follow-up and reduce client fatigue related to this process in cases where multiple providers or organizations may be involved in follow-up data collection. Also of importance for planning and preparing consent forms is determining who must provide signatures. This is particularly important when working with adolescent populations.

## **Locator Form**

The locator form is one of the most important tools for locating clients for follow-up (Hall et al., 2003). A locator form should be used to collect information about each client at intake and should be updated frequently. The locator form is most useful if it is filled out as completely as possible—partial information will not facilitate client tracking and locating tasks. Getting as much information as possible at intake/baseline will save time and money later.

Monitoring and/or auditing of locator forms is important in determining whether complete locator information is routinely collected. If the staff responsible for collecting locator information does not understand the importance of obtaining complete and detailed information, there may be a need for training around this aspect of the follow-up process. According to Hall et al. (2003), at a minimum, the locator form should collect the following information:

1. Full name
2. Date of birth
3. Nicknames or aliases

4. Place of birth
5. Driver's license number
6. Social security number
7. Full residence address and phone number
8. Best mailing address and phone number
9. Work address and phone number
10. Name, address, and phone number of all immediate relatives and friends
11. Name of caseworkers, doctors, clinics, or other agencies with which the client has regular contact
12. Regular hangouts

It is good practice to ask the client to inform the people listed on the locator form that they are participating in a study, and that they have given the program permission to contact these people if needed.

Program providers that will be conducting follow-up data collection should determine who will be responsible for keeping and updating locator form information and at what point providers will be given locator form data for use in locating clients and scheduling follow-up appointments. Because it may be unknown which provider will be responsible for a client at the point that follow-up is due (or will be the last provider to serve the client before follow-up), it is important to determine how locator information will be shared with providers, and who will be responsible for sharing this information at the appropriate time.

## **Verification Protocol**

Within 7–10 days of collecting locator form information, program staff should verify the names, addresses, and phone numbers provided by the client to ensure that they are complete and correct.

An easy and cost-efficient way to verify client address data is to send a “thank you” card within 7 days of study intake. This card will give the program an opportunity to remind the client about the follow-up data collection point and the incentive, while providing a way for the program to ensure that the address is correct. If the card is returned or undeliverable, this will be a cue for the program to collect new address information from the client.

Example of “thank you” card content:

Dear John Doe,

Thank you for agreeing to participate in the health study being conducted by ABC Agency. We appreciate your input, and look forward to speaking to you again on Tuesday, February 3, 2008, at 2:00 p.m.

Remember, you will receive \$20 when you complete your follow-up interview. If you have any questions between now and Tuesday, February 3, 2008, please feel free to contact us at 1-800-123-4567.

Sincerely,  
Jane Follow-Up

In addition to verifying the client address, it is essential to verify the other contacts provided on the locator form. There are a number of ways to do this, including

1. Use the World Wide Web
2. Use telephone and other directories
3. Send an introductory note to each locator contact
4. Call contacts while the client is in the office to let them know that they may be contacted in the future for assistance in locating the client

Passetti, Godley, Scott, and Siekmann (2000) provides specific information and links for using the World Wide Web for verifying locator information. Additionally, Hall et al. (2003) provides an extensive list of Web and other electronic resources for use in verifying locator information. If the information on the locator form cannot be verified, staff may contact the client to review the information as quickly as possible. “The difficulty and costs in locating participants increase as the time between collecting the locating information and using it increases” (Scott, 2004, p. 25).

## **Protocol for Maintaining Contact and Confirming Appointments**

Once the client has been recruited into the study, signed appropriate consents, and provided locator information, it is important to schedule his or her follow-up appointment. A great way to help the client to remember the appointment is to provide a laminated schedule card for the client to take away from the initial meeting (Scott, 2004). An example is provided below. Be sure to include the following information: (1) the date, time, and location of the appointment; (2) the incentive to be provided for participation; and (3) a phone number to call with questions or changes to availability. It may be useful to create a logo for use with the data collection and to include that logo on all forms, letters, and items associated with the study. This will create continuity and recognition throughout the process.

**Receive \$20.00**  
**When you complete your follow-up interview!**

**When:       Tuesday, February 3, 2008**  
**at 2:00 PM**

**Where:      ABC Agency**  
**123 Main Street, Suite 200**  
**Any City, USA**

**ABC Agency**  
**1-800-123-4567**

It is important to maintain periodic contact with the client between intake and follow-up data collection (Hall et al., 2000; Scott, 2004; Scott et al., 2006). You may create a series of mailings, including birthday and holiday cards, newsletters, and/or flyers to send every 4–6 weeks post intake. This will not only allow continuous engagement with the client, but returned mail will alert staff that locator information has become obsolete. Your program should create a consistent protocol for sending mailers to clients that includes the following information:

1. Who is responsible for sending mailers?
2. At what points will mailings go out?
3. Where will mail be returned if addresses are no longer good?
4. Who will be responsible for checking locator information if mail is returned?
5. How will new information be captured, stored, and shared as needed?

Staff should begin attempting to confirm follow-up appointments at least 45 days prior to the follow-up appointment. Staff should conduct some sort of activity in attempt to confirm the client at least every 24 to 48 hours until confirmation is accomplished. Confirmation is accomplished when staff speaks directly to the client (Scott, 2004). Confirmation activities include, but are not limited to, the following simultaneous actions:

1. Letter to the client regarding upcoming appointment
2. Phone calls to client's residence and best contact phone number
3. Letters to individuals and agencies listed on locator form
4. Phone calls to individuals and agencies listed on locator form

5. Phone calls to agencies with whom ATR program has release of information agreements
6. Checks of criminal justice, hospital, and other agencies to determine if client is institutionalized

Once confirmation is accomplished, your program should send a confirmation letter detailing the agreed-upon scheduled appointment. Finally, the program should make reminder telephone calls at least at 7 days *and* 24 hours prior to the follow-up appointment.

## Monitoring

With the volume of clients expected to be served by each ATR program, ongoing monitoring of follow-up activities and progress will be essential, regardless of who will be responsible for conducting follow-up data collection. “A mechanism for monitoring protocol compliance is necessary and provides staff and supervisors with the information they need to manage studies and cases effectively and efficiently” (Scott, 2004, p. 27). In the absence of ongoing data reporting and monitoring, providers and programs often do not notice how things are going until it is too late to improve the problem.

The ATR follow-up monitor may need to incorporate weekly, or even daily, submissions of reports from the follow-up entity or entities. Periodic audits should be performed to ensure that recruitment, consent, and locator data collection for follow-up have been completed. These in-person audits should occur monthly during the first 6 months of the program, and should be prioritized, with the entities responsible for the highest volume of client tracking receiving the most frequent audits. Also, the ATR program may benefit from finding a way to link program follow-up data collection information with the voucher system.

Routine information sharing will be essential for monitoring progress and issues related to follow-up tracking and locating. Therefore, it is recommended that programs institute routine discussions between program, follow-up, and provider staff regarding what is going on with follow-up, as well as using weekly e-mails to update and remind staff about the process. If an entity or organization other than the providers will be responsible for conducting follow-up tasks, it will be important for them to receive regular updates from the provider regarding whether the client is receiving the services, when the last time the client came in for services, and whether there is any new locator information.

Tracking staff should be recording the date, time, and outcome for each tracking activity performed. It is best to keep this information in a tracking database, so that the ATR program staff or monitoring staff can easily monitor and run reports on this information. This information should be input and documented in real time—otherwise information will be forgotten. If an activity is not documented, it may as well have not have occurred. The database should enable ATR program or monitoring staff to view reports such as the following (at a minimum):

1. Number of clients with intakes
2. Dates of intakes
3. Dates of each tracking activity

4. Failures to verify or confirm clients
5. Actions taken when failures occur

It may also be helpful for tracking and locating staff to use checklists that they can send to the monitor as follow-up tasks are completed. To employ this option, the ATR program will need to create standardized forms and checklists for documenting the tracking activities.

The ATR program will need to determine the incentives to provide for completing follow-up tasks and successfully obtaining follow-up data as well as the consequences for failing to complete these tasks. Your program must consider the following questions for the monitoring tasks:

1. Who is responsible for monitoring each of the follow-up activities?
2. What is the process for the follow-up entity to submit reports?
  - a. Frequency
  - b. Format
  - c. Data elements
3. What is the process for reviewing follow-up activities (e.g., chart audits; calls to clients to ensure follow-up was complete)?
4. If staff involved in study intake is different from follow-up staff, what is the process for reminding follow-up staff about milestones?
5. What are the rewards and consequences associated with follow-up activities?
6. How will the ATR program keep the follow-up entity on course to ensure that follow-up activities will be done?

## **5. A Successful Model for Tracking Clients**

In conclusion, a successful model for tracking and following up on individuals over time has been created and tested in multiple situations (Scott, 2004 Scott et al., 2006). This model has been used by CSAT grantees and has enabled them to achieve follow-up rates of 80% or better. According to this model, as noted earlier in this document, tracking for follow-up should begin at the start of the project, and should be ongoing until all clients are accounted for. Before the first client enters the program, important staffing and budget decisions need to be made, contracts and MOUs should be in place, connections should be forged with other agencies and organizations to facilitate obtaining releases of information as needed, and forms and materials should be created and ready for use (see Chapter 3).

Forms and materials for use in tracking and follow-up include the following:

1. Logos to be used on all follow-up documents
2. Recruitment script
3. Consent form
4. Locator form
5. Appointment cards
6. “Thank you” notes
7. Birthday and holiday cards
8. Appointment reminder letters
9. Report forms
10. Tracking logs and databases

Within 7 days of the intake session, a “thank you” card should be sent to the client, welcoming him or her to the study, thanking him or her for participating, and reminding him or her about the incentive to be received upon follow-up. This card will assist the program in verifying the client’s contact information. If the card is returned undeliverable, this will alert the program that the address information is incomplete or incorrect. Also within 7–10 days of intake, the contact information provided on the locator form should be verified. If the contacts cannot be verified, the program should contact the client as soon as possible to update the information.

Between intake and follow-up, client contact should be maintained via mailings every 4–6 weeks. These mailings may include items such as birthday and holiday cards, newsletters, and flyers. Not only will these mailings help to keep the client engaged in the study, but they will also assist the program in ensuring that contact information is up to date. As with the “thank you” card, if mailings are returned or undeliverable, this will signal that the locator data must be updated.

Approximately 6 weeks prior to the scheduled follow-up, the program should begin working to confirm the client for follow-up. This process involves daily activities such as mailings, telephone calls to the client and client contacts, and outreach until direct contact with the client is made. A client is considered “confirmed” once direct contact is made with the client, and the scheduled follow-up appointment is confirmed or changed.

Once confirmation has been accomplished, an appointment reminder should be mailed to the client, indicating the date, time, and location of the follow-up appointment; providing a means for the client to contact the follow-up staff if needed; and reminding the client about the incentive for attending the follow-up session. Seven days prior to the scheduled follow-up appointment, a phone call reminder should be made. Another phone call reminder should be made 24 hours prior to the scheduled appointment.

In order for this protocol to be effective, follow-up tracking activities should be closely monitored by the ATR program. That means that detailed tracking information must be kept by the staff conducting the follow-up tracking activities, and this information should be regularly shared with the monitor. Daily reports indicating tracking activities conducted for each client, statistical information regarding success of verification, confirmation, and follow-up data collection should be standardized and required. Regular case meetings should be held during which progress and issues are discussed. In addition, at all regular staff meetings, there should be discussions of open cases due for follow-up and those cases of hard-to-locate clients.

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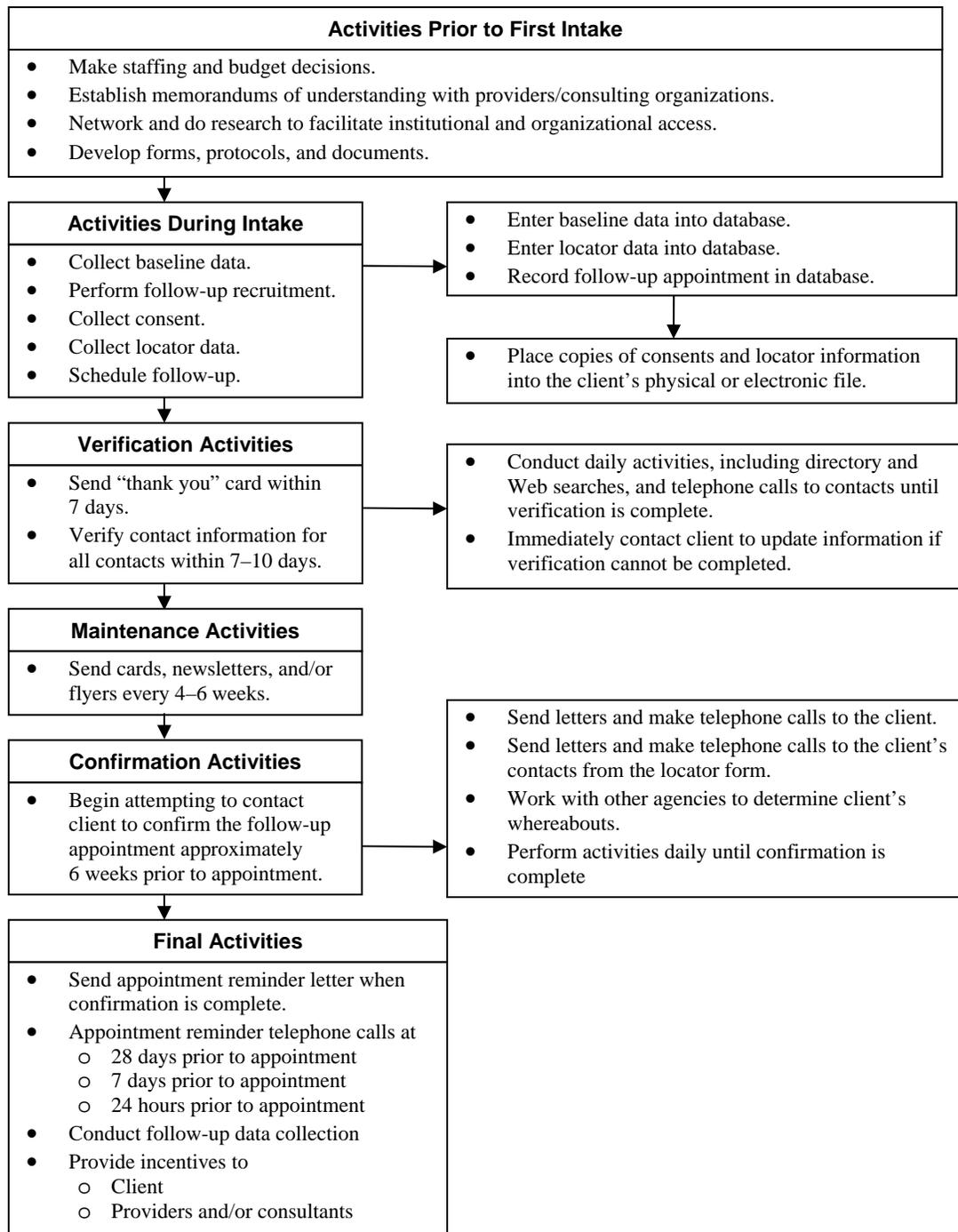
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## Appendix A. Responsibility Matrix

	Who (Job Title)	Procedures for Completion	Monitoring Responsibility	Monitoring Process	Monitoring Frequency
Releases of information (consent to gain information from programs or systems)					
Memorandums of understanding with providers if they will be conducting follow-up					
Recruitment script					
Consents					
Locator form					
Verify locator data					
Maintain contact					
Confirmation process					
Client incentives					
Notification that follow-up is due					
Reporting progress					
Documentation					
Establish a database for keeping track and running reports					

## Appendix B. Client Tracking and Follow-Up Activities Flowchart<sup>1</sup>



<sup>1</sup> Developed by Christy Scott, Ph.D., Chestnut Health Systems.

## Appendix C. Follow-Up Article Tracking Form

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Allott, K., Chanen, A., & Yuen H. P.	2006	Journal of Nervous Mental Disorders, 194(12), 958–961	Attrition bias in longitudinal research involving adolescent psychiatric outpatients	Youth, adolescent outpatients in Australia	Meticulous log of contact attempts. Informed consent. Incentive. Phone calls to participants or informants, letters, medical records or clinical staff, online phonebook, electoral roll, registry of births, deaths, and marriages. Interviews in homes and after business hours. Rescheduling of missed appointments. Plan and budget for sufficient follow-up time. Collect contact details of significant others. Use multiple follow-up strategies.	96% at 2 years.	
Armistead, L. P., Clark, H., Barber, N. K., Dorsey, S., Hughley, J., Favors, M., & Wykoff, S. C.	2004	Journal of Child and Family Studies, 13(1), 67–80	Participant retention in the Parents Matter! Program: strategies and outcome	African Americans, families	Recruitment through community liaisons, which were the main contacts for both participants and recruiting community organizations. Careful selection during hiring process for community liaisons and enrollment/assessment staff (people who are courteous and non-judgmental). Detailed and accurate information presented to study participants. Eligibility screener asked for family friends and/or relatives contact information. Enrollment staff was trained to help computer-naive participants learn needed computer skills for study. Asked for verification of contact information at every assessment interval using “retention forms.” Both verbal and paper reminders handed out at each assessment session. All contact information held in frequently updated database. Incentives: \$25 for child care or transportation for each session, light snacks and drinks provided, each participating child choose a small toy (that costs about \$2), an additional \$25 provided to those who completed all assessment sessions. Frequent reminders about incentives.	93% at 1 year	Parents Matter Project, retention, African Americans, longitudinal studies

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Brown-Peterside, P., Rivera E., Lucy, D., Slaughter, I., Ren, L., Chiasson, M. A., & Koblin, B. A.	2001	American Journal of Public Health, 91(9), 1377–1379	Retaining hard-to-reach women in HIV prevention and vaccine trials: Project ACHIEVE	Women, hard-to-reach populations	Recruitment: street outreach, newspaper ads, flyers, posters, and tabling in clinics and at health fairs. At recruitment, asked for names of two contacts who didn't live with participant, as well as contact information for physician and case manager. Asked participant to sign consent allowing them to contact any of these four people to find their whereabouts. This contact information was verified twice during the year of the project (3 months, 9 months). Incentives: At each visit, given \$20 for participating, and a \$3 Metro card for transportation, as well as small gifts (such as condoms). Flexible appointment scheduling. Counseling services also probably helped increase participation. Dealt with missed appointments by making phone calls and sending letters, and then home visits at several different times of the day. If these strategies didn't worked, they checked to see if participant had become homeless or become incarcerated. For those in the homeless shelter system, sometimes managed to renew contact. Retention support: one full-time staff member, financial support for home visits (such as car service), and a computerized tracking system.	88% at 1 year	
Bull, S.S., Lloyd, L., Rietmeijer, C., & McFarlane, M.	2004	AIDS Care, 16(8), 931–943	Recruitment and retention of an online sample for an HIV prevention intervention targeting men who have sex with men: The Smart Sex Quest Project	Men who have sex with men (MSM)	N/A	N/A	Details on what it takes to identify, recruit, and retain participants in Internet interventions, so that we can test their efficacy and effectiveness. This looks at intervention to prevent HIV in MSMs.
Claus, R. E., Kindleberger, L. R., & Dugan, M. C.	2002, Jan-Mar	Journal of Psycho-active Drugs, 34(1), 69–74	Predictors of attrition in a longitudinal study of substance abusers	Substance abusers	Early initial follow-up interview by phone (one week post-baseline) in addition to 1-month follow-up, whenever possible. Identify three or more contacts at baseline. Recommend obtaining releases permitting contact with previous substance abuse and psychiatric treatment providers. Take extra effort to engage and retain participants with high attrition risk factors (male, unmarried, high school dropouts, unemployed etc.).	77% at 12 months	

Setting Up a System for Client Follow-Up

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Coen, A. S., Patrick, D. C., & Shern, D. L.	1996, Nov.	Evaluation and Program Planning, 19(4). Special issue: Innovative Methodologies for Longitudinal Evaluation of Human Service Programs. pp. 309–319.	Minimizing attrition in longitudinal studies of special populations: An integrated management approach	Individuals with serious and persistent mental illness (SPMI)	Integrated approach includes all parties: community, respondents, field interviewers, management. Respect for respondent, ensuring confidentiality, community involvement, log sheet, electronic database, staff trained in engagement, flexibility between interviewers, encouragement for respondents to call collect, use of answering services, stressed importance of well-trained interviewers, use of part-time interviewers for flexibility and to avoid burnout. Mail and telephone, directory assistance, locator forms, detailed log sheets with info such as respondents' work schedules, etc. Consent procedures allowed for staff to obtain location info from community health centers. Interviewer ingenuity to enter the respondent network. Interviewer persistence. Rigorous interviewer selection criteria. Adaptation of protocols to subject characteristics.	95% on average	
Cohen et al.	1993	Evaluation Review	Tracking and follow-up methods for research on homelessness	Homeless, mentally ill	Collection of contact information, field tracking, establishing agency contacts, public and private databases, vouchers/incentives.	86% at 4 months, 83% at 12 months	
Conover, S., Berkman, A., Gheith, A., Jahiel, R., Stanley, D., Geller, P.A., Valencia, E., & Susser, E.	1997	Bull N Y Acad Med. 74(1), 90–108	Methods for successful follow-up of elusive urban populations: An ethnographic approach with homeless men	Homeless, men	Focus on trust and continuity, move away from conventional methods, train interviewer to obtain "insider's perspective," obtain information about family and community contacts, incentives, avoid structure in interviews to maintain trust/good rapport, stress a "personal touch"	N/A	
Cotter, R. B., Burke, J. D., Loeber, R., & Navratil, J. L.	2002	Journal of Child and Family Studies, 11(4), 485–498(14)	Longitudinal research: A case study of the developmental trends study	Youth and families, reluctant or resistant participants, transient or hard to locate participants	Electronic databases, interviewer persistence, review all previously collected information, use Internet directories and prison/military Web sites, incentives.	98% to 100%	

Setting Up a System for Client Follow-Up

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Cottler, L. B., Compton, W. M., & Ben-Abdallah, A.	1996, Jul.	Drug and Alcohol Dependence, 41(3) 209–217	Achieving a 96.6 percent follow-up rate in a longitudinal study of drug abusers	Substance abusers	Comprehensive phone, systems, and field tracking, creative team-work and communication, persistence. Locator form (including aliases, service providers, employers, etc). Free drug treatment offered. Letters. Contact log. Toll free number. Caller ID. Credit reporting agencies, Hospitals, corrections, coroner's office, motor vehicles dept. voter registrations, etc. (agency contacts). Public and private databases. Visits to homes, neighborhoods, friends, etc. at strategic times during day. Incentives offered to participant and finder's fee (and bonus for converting a reluctant participant) offered to families.	96.6% at 18 months	
de Graaf, R. et al.	2000	American Journal of Epidemiology 152(11), 1039–1047	Psychiatric and Sociodemographic Predictors of Attrition in a Longitudinal Study The Netherlands Mental Health Survey and Incidence Study (NEMESIS)	General population in the Netherlands	Mail. Phone calls. Field tracking. Municipality records. Change-of-address cards.	79.4% at 1 year	Discusses sociodemographic effects and psychiatric disorders on three types of attrition.
Desmond, D. P., Maddux, J. F., Johnson, T. H., & Confer, B. A.	1995, Mar-Apr	Journal of Substance Abuse Treatment, 12(2), 95–102	Obtaining follow-up interviews for treatment evaluation	Opioid users admitted to methadone maintenance	Ten recommended procedures: (1) complete locator info at baseline, (2) informed consent, (3) incentives, (4) care in selecting follow-up staff, (5) comprehensive tracking log, (6) develop and exploit institutional info sources (prisons, service providers, etc), (7) short follow-up interviews, (8) conduct interview where participant is found and willing to be interviewed, (9) provide adequate resources for travel, (10) ample time for field work. Locator had 21 discrete items. Mailed letters. Finder's fee offered to relative. Telephone calls. In-person visits. Inquiries into criminal justice system. Patience, ingenuity, persistence.	98% overall	

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Farrington, D. P.	1991, May	Journal of the American Academy of Child & Adolescent Psychiatry, 30(3), 369–374	Longitudinal research strategies: Advantages, problems, and prospects	General	N/A	N/A	Outlines advantages of longitudinal over cross-sectional surveys. Outlines problems with traditional single-cohort longitudinal surveys. Suggests multicohort strategy.
Fernandez, M. I., Varga, L. M., Perrino, T., Collazo, J. B., Subiaul, F., Rehbein, A., Torres, H., Castro, M., & Bowen, G. S.	2004	AIDS Care, 16(8), 953–963	The Internet as recruitment tool for HIV studies: viable strategy for reaching at-risk Hispanic MSM in Miami?	MSM, Hispanics	Hispanic MSMs were recruited through chat rooms. To participate in the study, men presented themselves at a community assessment site, where a staff member was stationed to set participants up to take an online survey. Of the men who showed up at the community assessment sites, 98% were eligible to participate in the study.	N/A—focus on recruitment	Looks at use of the internet for recruitment, specifically in MSM HIV studies

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Frank, G. C., Nader, P. R., Zive, M. M., Broyles, S. L., & Brennan, J. J.	2003	Journal of School Health, 73(2), 51-57	Retaining school children and families in community research: Lessons from the Study of Children's Activity and Nutrition (SCAN)	Youth and families	Three methods of frequent contact with participating families: (1) telephone contact: For each measurement wave (every 6 months), each family contacted by phone to verify address and child's name and school. An additional scheduling call was made one week prior to each visit; (2) newsletter: Every 6 months, an informative newsletter was mailed to each family. The newsletter included a request to update the project officer about residency, telephone, or contact information was included; (3) mail contact: All letters, including an annual birthday, were stamped with "Address Correction Requested" to alert the post office to return the letters if they were not delivered and to provide a new address if this was available. Additional tracking procedures: Asked for updated contact information for participant and three contacts at each visit (and contacted them if needed), searching records at the County Register of Voters, department of motor vehicles, the county school district, and Internet searches. Other reasons for positive staff reception: (1) using staff of the same ethnicity, (2) training staff to know the geographic area where participants live, (3) updating staff on schedules and activities in the communities and schools which could conflict with screen days and times, (4) conducting the measurements in the homes, (5) dealing confidentially with family data, and (6) informing participants of potential studies on the future. Incentives: gifts with the study logo on them (water bottles, t-shirts, etc), \$50 for each child at each measurement wave, \$50 for one parent at each measurement wave.	48% at 14 years	

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Gregory, M. M., Lohr, M. J., & Gilchrist, L. D.	1992, Feb	Evaluation Review, 16(1), 69–81	Methods for tracking pregnant and parenting adolescents	Pregnant and parenting adolescents	Extensive locator form (family, friends, service centers, expected delivery date). Prepaid change-of-address postcards, magnets, and business cards provided to respondents. Toll-free number and personal phone coverage for research center. Data files kept current. Emphasis on building rapport with respondent's network. Service centers proved very helpful in relaying messages. Holiday cards. Positive reinforcement to respondents initiating contact. Extensive and detailed call logs. Advance recontact attempts for difficult cases. Escalating cash incentives. Free services, gift for baby. Consistent interviewer. Confidentiality stressed.	97% to 99% (over 5 years)	
Gwadz, M., Columbia University New York State Psychiatric Institute, Columbia-Presbyterian Medical Center, HIV Center for Clinical & Behavioral Studies, U.S., & Rotheram-Borus, M. J.	1992, fall	AIDS Education and Prevention, Suppl, 69–82	Tracking high-risk adolescents longitudinally	Youth, adolescent (particularly gay male runaways)	Incentives for community-based orgs (CBOs), participants, and interview staff. Development of project identity at CBOs and ongoing rapport-building. Hiring CBO agency director as "tracking consultant" to liaise with social services, etc. Locator form. Database including "hints" obtained during interviews (e.g. going to jail, is pregnant). Confidentiality ensured, including Government shield that prohibited data being subpoenaed. Asked locator form contacts for further contacts. Selection, training, and supervision of interviewing staff, who were compensated per interview completed. Interviewer diversity. Social support, such as group counseling, offered to interviewers due to high risk for burnout. Private investigators. Enticing certified and overnight mail envelopes. Cash incentives. Eligibility for cash prize lottery for calling with new tracking info. Directory assistance. Reverse phone book. Online databases. Newsletters. Parties. Reminders such as belts or bracelets. Concert tickets. Child social service agencies. Police departments, universities, group homes, etc. Home visits. Siblings and young extended family members. Foster families.	92% on average	
Hansen, W. B.	1990, Dec	Evaluation Review, 14(6), 677–685	Attrition in substance abuse prevention research: A meta-analysis of 85 longitudinally followed cohorts	Substance abusers	N/A	Various studies (see article)	Meta-analysis of published and unpublished school based substance abuse prevention programs totaling 85 distinct cohorts.

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Hatchett, B. F., Holmes, K., Duran, D. A., & Davis, C.	2000	Journal of Black Studies, 30 (5), 664–675	African Americans and research participation: The recruitment process	African Americans, families	Researchers found that telephone contact alone was not effective with potential participants who were African American. To recruit African American participants, researchers (1) used ethnically-matched staff; (2) compiled a list of key community members and organizations, and contacted them; (3) sent information about the study to African American churches in the area, first by mail, then by telephone, and then in person with informal meetings; (4) gave presentations to local community groups, focusing on subjects that they know would interest potential participants. Also they used: local radio ads, advertisements in African American newspapers, flyers posted in strategic locations (such as bookstores, college campus offices, and dorms). The vast majority of African American participants reported hearing about the study through “word of mouth,” emphasizing the importance of research study contact with community individuals who will spread the word (“facilitators or lay workers”).	N/A—focus on recruitment	This article addresses the unique approaches to take to secure African American participants
Hough, R. L. et al.	1996	Journal of Consulting and Clinical Psychology	Recruitment and retention of homeless mentally ill participants in research	Homeless, mentally ill	Anchoring, phone tracking, agency tracking, field tracking, mail tracking, incentives, interpersonal trust, appeal to altruism.	85% after 6 months, 76% after 12 months, 79% after 18 months	This article discusses tracking methods in general and then provides a case study of a 1995 Homeless Demonstration Research Project in San Diego (Wright et al. 1995).

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Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Howard, J.	1992	NIDA Research Monograph, 117, 155–165	Subject recruitment and retention issues in longitudinal research involving substance-abusing families: A clinical services context	Youth and families, substance abuse	Recruitment/referral: referral sources—first established collaborative relationships with a variety of referral sources, such as health or treatment center for substance-abusing individuals, or in States where infants exposed prenatally to drugs are reported as being at high risk for child abuse and neglect, an additional referral source would be the local child protective services agency and/or the family court system. Research “invitation”—should include a clear description of the research project as well as of the participants’ role, and convey an attitude of sensitivity to for the subject. Important staff approaches: personal, one-on-one approach; availability on weekends/evenings, must have some staff that provide services, while others conduct evaluations. Important relationships: extended family, community agencies. Important staff development/training: learn roles of various organizations with which clients have frequent interaction (Decision Support Systems, etc.), learn about family systems/functioning learn how to assess potentially dangerous situations.	Various studies (see article)	
Jaycox, L. H., Ebener, P., Damesek, L., & Becker, K.	2004	Journal of Trauma Stress, 17(2), 113–121	Trauma exposure and retention in adolescent substance abuse treatment	Youth, substance abusers	N/A	N/A	Examines whether trauma exposure and related symptoms interfere with adolescent adherence to drug treatment.

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
LaFazia, M. A., Kleyn, J., Lanz, J., Hall, T., Nyrop, K., Stark, K. D., Hansen, C., & Watts, D. H.	1996	NIDA Research Monograph, 166, 52–67	Case management: A method of addressing subject selection and recruitment issues	Women, pregnant women, substance abusers	The project implemented the following five recruitment-specific activities: (1) a recruitment committee was formed to meet monthly to review recruitment; (2) the recruitment protocol was enhanced to incorporate existing knowledge about treatment engagement techniques and limit the amount of time spent on recruiting individual women; (3) a recruitment coordinator was hired to survey social services and health care providers, especially providers of services to adolescents, and assess the usefulness of direct recruitment; (4) other project staff members, especially those from the chemical dependence treatment program, were encouraged to become involved in recruitment efforts through providing ongoing presentations to health care and social services clinics and agencies; and (5) project staff members encouraged representatives of potential referral sources to visit the treatment facility.	N/A—focus on recruitment	
Leonard, N. R. et al.	2003, Jun	AIDS Education and Prevention, 15(3), 269–281	Successful recruitment and retention of participants in longitudinal behavioral research	HIV-affected individuals	Incentives for each level of investigation. Collaboration with community-based organizations. Organizational structure and project management (computer tracking systems, audio taping interviews, quality assurance checks, regular staff meetings, productivity reports for interviewers). Selecting and training motivated field staff (culturally compatible, resilient, nonjudgmental, detail-oriented, persistent staff with basic knowledge of behavioral research. Rapport-building, staff incentives including quotas and payment per interview completed). Participant-motivated interventions (showing respect for participant’s schedule, highlighting benefits of participating [e.g. obtaining services, helping peers], reframe obstacles as challenges to be solved in collaboration). Contacts collected at all data collection points. Holiday cards, brightly colored reminder flyers, certified or overnight mail, toll-free number, clear project logo, timely payment of stipends, certificates of participation at project milestones, mugs or key chains with logo, newsletters with alumni stories. Incentives to contacts who help to locate. Active listening, appropriate social service referrals. Online databases. Use of Motor Vehicles Administration and Social Security. Asking permission to use ringleader in social network as a contact.	N/A	

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Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
McKenzie, M. et al.	1990	Journal of Health Care for the Poor and Underserved	Tracking and follow-up of marginalized populations	Marginalized (homeless, low income, substance abusers)	Collection of contact information, thorough organization, staff training, phone tracking, mail tracking, incentives, establishing rapport/trust, assurance of confidentiality, agency-based tracking, attention to safety concerns.	75% to 95%	This article is a review of many longitudinal studies.
Mills, C. A., Pederson, L. L., Koval, J. J., Gushue, S. M., & Aubut, J. A.	2000, Mar	Journal of School Health, 70(3), 107-112	Longitudinal tracking and retention in a school-based study on adolescent smoking: Costs, variables, and smoking status	6th graders in Canada	Locator form at baseline for both school and home contacts. Phone calls. Multiple mailings. Infospace.com. School board. Stamped return envelopes provided for updates.	96% (at 8th-grade follow-up) and 91% (at 11th-grade follow-up)	
Miranda, J., Azocar, F., Organista, K. C., Munoz, R. F., & Lieberman, A.	1996	Journal of Consulting and Clinical Psychology, 64(5), 868-874	Recruiting and retaining low-income Latinos in psychotherapy research	Latinos, low-income	Particular strategies that have worked in past studies with Latina/os: (1) careful, individualized approach (personal phone calls in which researchers asked about remembered family details, house visits, birthday cards, birthday celebrations and videos of mother and child as incentives [in addition to money]); (2) taking care of family demands (providing childcare, transportation), (3) making more "warm" research environment (giving participants cold drinks and coffee, letting participants bring in food to share with the group); and (4) recruiting through familiar and trusted medical providers, such as family doctors/PCPs. Also mentioned several accessibility needs for Latino/as: bilingual and bicultural staff, treatment in Spanish, free care.	Various studies (see article)	This article addresses the unique approaches to take to secure Latino participants
Nuttbrock, L. H. et al.	1997	Addiction	Pre- and post-admission attrition of homeless, mentally ill chemical abusers referred to residential treatment programs	Homeless	N/A	N/A	This article addresses a preferred type of treatment (therapeutic communities) which may increase retention and attrition. This article also discusses the psychopathology involved in attrition.

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Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Palinkas, L. A., Atkins, C. J., Noel, P., & Miller, C.	1996	NIDA Research Monograph, 166, 87–109	Recruitment and retention of adolescent women in drug treatment research	Women, adolescents, substance abusers	This article mostly focused on the demographic characteristics that predicted decreased participation and dropout. They did mention that they recruited teens through several local health clinics and medical centers geared toward adolescents, as well as the judicial system and the public schools. But, they found that pregnant women recruited through noninstitutional sources (current or former study participants, self-referral, parent/guardian), were more likely to remain in the study and attend more sessions. This suggests that recruitment and retention can be improved by “making greater use of adolescent social support networks.”	Not reported: focused on comparing traits of participants vs. nonparticipants	
Passetti, L. L., Godle, S. H., Scott, C. K., & Siekmann, M.	2000	American Journal of Evaluation, 21(2), 195–203	A low-cost follow-up resource: Using the World Wide Web to maximize client location efforts	Pregnant/postpartum women in residential substance abuse treatment	Internet tools: databases, phone directories, reverse look-ups (e.g. Infospace.com), Government agencies, (e.g. Social Security Death Index), criminal justice system, media, maps, search engines. Use Internet to search for contacts of participants.	93% overall	
Namerow, P. B., Philliber, S. G., & Hughes, M.	1983, Jul-Aug	Family Planning Perspectives, 15(4), 172–176	Follow-up of adolescent family planning clinic users	Sexually active youth, adolescents	Three-item locator form. Reduced intervals between appointments after one missed appointment. Patient counsel on importance of follow-up. Mail and phone calls (including evenings and weekends).	63% at 6 months	
Pollastri, A. R., Pokrywa, M. L., Walsh, S. J., Kranzler, H. R., & Gelernter, J.	2005	Experimental and Clinical Psychopharmacology, 13(4), 376–380	Incentive program decreases no-shows in nontreatment substance abuse research	Substance abusers	Incentives (up to \$15 value) increased participant attrition. Each incentive for homeless persons was given a point value, and participants who showed up for follow-up interview were allowed to choose up to 10 points in incentives.	58% to 59%, but incentives decreased “no-shows” by ~15%	
Pollio, D. E., Thompson, S. J., & North, C. S.	2000	Community Mental Health Journal	Agency-based tracking of difficult-to-follow population	Youth, homeless	Locate youth through a primary relationship. Calling social workers NOT a good way to track. “Creativity” in tracking is critical. Consistency in effort is key. Protocol developed with community agencies with consistent implementation is necessary.	69% located	

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Ribisl, K. M., Walton, M. A., Mowbray, C. T., Luke, D. A. et al.	1996, Feb	Evaluation and Program Planning, 19(1), 1-25	Minimizing participant attrition in panel studies through the use of effective retention and tracking strategies: Review and recommendations	Juvenile delinquents, people with mental illnesses, drug and alcohol abusers	Comprehensive locator forms. Establish formal/informal relationships with public and private agencies. Create a project identity. Emphasize importance of tracking to project staff. Use simplest and cheapest tracking methods first. Make research involvement convenient and rewarding for participant. Expend greatest tracking efforts and initial follow-up periods. Customize tracking methods to each participant. Phone calls, mailings, contact old and new schools, driver's records, ask about former classmates, contact jails, hospitals, incentivize families or participants, relationship-building with all participants, holiday cards. For substance abusers: reimbursement for transportation/child care, certified mail, treatment programs, formerly addicted friends, credit and telephone companies, welfare courts, vital statistics, etc.	Various studies (see article)	
Robles, N., Flaherty, D. G., & Day, N. L.	1994	American Journal of Drug and Alcohol Abuse, 20(1), 87-100	Retention of resistant subjects in longitudinal studies: Description and procedures	Women, pregnant women, substance abusers	This article focuses on techniques used to encourage participation of "resistant subjects." By the article definition, resistant subjects were women for whom researchers had valid contact information, and who, while they did not refuse to participate, were reluctant to schedule appointments and frequently missed scheduled appointments. They used the following techniques: (1) telephone calls: frequent and sometimes long conversations about reasons for participation difficulties; (2) letters: first form letters, and then form letters with handwritten notes; (3) home visits by two staff members; (4) home assessment as a fall-back; (5) alternative meeting arrangements: flexibility of assessment time and location; (6) transportation: taxi fare, or project staff providing transportation; (7) child care; (8) incentives: tangible (holiday gifts, \$5 more in incentive for resistant subjects, free exam that occurred as part of the assessment) and Intangible (full explanation of project procedures, and the larger importance of the study); 9) concern for other problems: researchers recognized and worked with participants to deal with difficulties in other areas of their life.	95% at 3 years	

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Sayre, S. L., Schmitz, J. M., Stotts, A. L., Averill, P. M., Rhoades, H. M., & Grabowski, J. J.	2002	American Journal of Drug and Alcohol Abuse, 28(1), 55–72.	Determining predictors of attrition in an outpatient substance abuse program	Substance abusers	N/A	N/A	Examines relationship of demographic, drug use severity, and psychological factors with treatment attrition.
Schanzer, B. et al.	2007	American Journal of Public Health	Homelessness, health status, and health care use	Homeless	Assertiveness, consistency in staff, constant contact over follow-up time, vouchers/incentives	85% at 6 months, 82% at 12 months, 79% at 18 months	
Scott, C. K.	2004, Apr	Drug & Alcohol Dependence, 74(1), 21, 16p; DOI: 10.1016/j.drugalcdep.2003.11.007; (AN 12778675)	A replicable model for achieving over 90% follow-up rates in longitudinal studies of substance abusers	Substance abusers	Clear staff roles and responsibilities. Obtain agency approval and partnerships. Develop written follow-up materials. Collect locator information. Develop and implement the Engagement, Verification, Maintenance and Confirmation (EVMC) Protocol. Monitor compliance with the follow-up protocol. Create standardized case tracking procedures. Case review meetings. Send thank you cards. Verify locator within 7 days post-intake. Monthly flyers, birthday cards. Confirmation letters, calls. Field outreach.	over 90%	
Scott, C. K., Sonis, J., Creamer, M., & Dennis, M. L.	2006, Dec	Journal of Traumatic Stress, 19(6), 757–769, 13p, 2 charts; DOI: 10.1002/jts.20186 ; (AN 23579799)	Maximizing follow-up in longitudinal studies of traumatized populations	Victims of trauma (including violence or abuse)	Building trust. Communication protocol for regular communication. Routine contact between interviews. Toll-free number. Best and worst times to call participants. Code name for the study. Same-gender interviewer. Assurance of participant safety. Certificate of confidentiality to avoid subpoenas. Collaboration between interviewer and respondent to combat avoidance behaviors during the interview. Minimize distress. Clear staff roles. Engagement of institutions and community orgs. Written materials (for consent, education, tracking). Develop EVMC protocol. Monitoring staff compliance. Flexible staffing schedules. Communicate that participation in study continues despite missed appointments. Detailed locator forms. "Where did you sleep last night?" for homeless (and other mobile) populations. Case review meetings with staff. Detailed attempt logs. Intensive early resource allocation.	96% on average	

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Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Simkin, L. S., Hirsch, L., Radosh, A., Middlestadt, S. E., Kaiser J., & Santelli, J. S.	2000, Sept	Journal of School Health, 70(7), 286–291	Strategies to maximize retention of a sample of young adolescents in a longitudinal evaluation of Healthy & Alive!	7th and 8th graders enrolled in HIV prevention intervention	Specific strategies to retain school districts, schools, teachers, and students. For students: confidentiality, letter signed by school district, passive consent of parents. Tracking info collected from teachers and students. Tracking database. School transfer information. Make-up surveys for absent students.	80% at 6 months, 73% at 18 months	
Steinhauser, K. E., Clipp, E. C., Hays, J. C., Olsen, M., Arnold, R., Christakis, N. A., Lindquist, J. H., & Tulsky, J. A.	2006	Palliative Medicine, 20(8), 745–754	Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research	Seriously ill, end of life, caregivers	Subject identification: hospital databases. Patient ascertainment: enrolled caregivers by asking the participant to identify the person who spends the most time with them, who provides most of their day-to-day care, assistance, and support; hired IT personnel training in database searches, research assistant to manually review hospital records, and a nurse to help to establish contact with hospitals, review clinic rosters, and coordinate staffing duties. Double-check logic of IT programming. Patient recruitment: first, letters—patients recruited through doctors, so doctors were given a letter to send to participant along with a packet of M&Ms. Recruitment letter to participants included a study brochure and a \$10 incentive for considering participation. Second, phone contact—follow-up calls within 7–10 days after receipt of the letter. Scheduled interviews within a week of the call. Recruiters learned to identify “passive refusal” participants early on, so that fewer resources were wasted. Also, learned the difference between “passive refusal” and the need to work to build participant trust (especially in African American population). Retention: First interview was at participant’s home to establish rapport. Set boundaries between research role and therapeutic role. Recognizing and being responsive to participants’ stressful life events, and thanking them for their commitment to the project. Encouraging staff support and self care (regular meetings, staff rewards such as breakfasts, staff social outings like bowling).	Not reported	

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Streissguth, A. P., & Guinta, C. T.	1992	NIDA Research Monograph, 117, 137-154	Subject recruitment and retention for longitudinal research: Practical considerations for a nonintervention model	Women, pregnant women, substance abusers	<p>Staffing: Staff should be similar to subjects in age, race, and social class, and have open attitudes about drinking/drug use. One full-time outreach position is needed just for maintaining the sample, scheduling appointments, transporting subjects, and doing mailings. Other techniques: naming the study appropriately, cover transportation costs and child care, flexible interview timing. Incentive: \$50/visit for parents; color books, balloons, \$20 for children, additional substantive assistance for mothers (buying diapers, etc). Contact information collected: At enrollment, participants asked about plans to move; for names, addresses, and telephone numbers of three contacts; for the name under which her telephone is listed; for her authorization to contact the telephone company for an unlisted number; for her social security number; for permission to obtain her address changes from social welfare agencies; and, if applicable, for the name of her social worker. Contact with participants: Sent out annual birthday cards and Mother's Day cards, and newsletters every 3 months. Envelopes were marked: "Address correction requested." Newsletter reminds mothers to notify about address or phone number change. Finding lost participants: Also used national credit check agencies, Government agencies, reverse telephone directories, and public records, such as death certificates and local court records for both civil and criminal offences. They also drove to the mother's last known address and talked with neighbors.</p>	85% at 7.5 years	

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Sullivan, C. M., Rumpitz, M. H., Campbell, R., Eby, K. K., & Davidson, W. S. II	1996, Sep	Journal of Applied Behavioral Science, 32(3), 262–276	Retaining participants in longitudinal community research: A comprehensive protocol	Low-income, abused women	Establish trust between interviewer and participant. Stress confidentiality, and potential for helping others. Locator forms, including safe and unsafe times to be contacted. Signed individual release forms giving permission to contacts, including Government agencies, to disclose her information. Reminder business cards with toll-free number, date of next interview, and incentive amount. Escalating incentive amounts. Participant-oriented and -tailored strategies. Phone calls to house, work. Repeat home visits, leaving notes. Mailings. Community-oriented strategies. Use aforementioned methods to reach alternate contacts. Allow adequate time to find participants. Maintain confidentiality. Contact participants midway between interviews. Establish rapport between one interviewer and participant over time. Perseverance. Penetration of participant's natural environments and social networks. Incentivize undergraduate interviewers with college credit for their services.	97% at 24 months	
Thompson, E. E., Neighbors, H. W., Munday, C., & Jackson, J. S.	1996	Journal of Consulting and Clinical Psychology, 64(5), 861–867.	Recruitment and retention of African American patients for clinical research: An exploration of response rates in an urban psychiatric hospital	African Americans, mentally ill	This article discussed strategies employed in a study with African American psychiatric in-patients. They identified four components of their strategy: (1) establish a strong working relationship between academic research center and mental health delivery site; (2) hire interviewers with previous experience working with the target population; (3) concentrate on providing extensive and consistent trainings across interviewers; and (4) address issues of cultural sensitivity, such as skin color and ethnicity matching between client and interviewer.	56% at 2 years	This article addresses the unique approaches to take to secure African American participants

Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Twitchell, G. R., Hertzog, C. A., Klein, J. L., & Schuckit, M. A.	1992	British Journal of Addiction, 87(9), 1327–1333	The anatomy of a follow-up	Men, mentally ill, substance abusers	<p>Record keeping: (1) prepare record keeping to maintain contact; (2) fully inform subject of follow-up; (3) obtain permission to use all available sources to locate subject; (4) record subject's full name, place of birth, and birthdate; (5) list permanent address if different from current address; (6) document social security number; (7) record relevant identification numbers, such as driver's license number, military ID, hospital record numbers, and student ID; (8) record other pertinent background information such as occupation, group affiliations, and academic major if a student; (9) record name, address, and phone numbers of 2 resource people; (10) obtain parent's full names and addresses.</p> <p>Study design: (1) stay in touch every 6 months (they send 2 cards each year, one on the birthday, and another 6 months later. Inside each card is a brief note stressing the importance of the follow-up, a request for updated contact information using enclosed postage-paid envelope of any address or telephone number), (2) request an update of addresses and phone numbers of relatives and friends every 2 years or so, (3) provide compensation for anything beyond filling out a simple postcard.</p> <p>Methods used to find "lost subjects": (1) trace the subject from the last known address—mark all letters "Forwarding Address Requested." If moved within 6 months, post office will return the letter to you with the new address. If more than 6 months, post office can perform address search for a small fee. Then, use certified mail to confirm that this is not the address; (2) begin to locate lost subjects by using the most obvious sources, such as hospital records, alumnus office or similar groups, police, prison, and jail records, Veterans Affairs and other military-related records; (3) turn to families and friends; (4) contact the DMV; (5) utilize other official records, such as Social Security Agency, marriage certificates and divorce records, correctional institutions, and National Death Registry; (6) turn to reverse phone directories; (7) look through telephone directories; (8) review the subject's file for any miscellaneous leads.</p>	8- to 12-year study, rate estimated at 98% or greater	

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Author	Date	Journal	Article Title	Population	Tracking Methods	Follow-Up Rates	Notes (General)
Vance, D.	1995	Psychological Reports 76(3 Pt 1), 783–786.	Barriers and aids in conducting research with older homeless individuals	Homeless	Service providers for information, posters with incentives mentioned, establish a rapport	N/A	This article paints a picture of issues in interviewing and tracking the homeless population in general.
Vander Steop, A.	1999	Journal of Child and Family Studies, 8(3), 305–318	Maintaining high subject retention in follow-up studies of children with mental illness	Youth, mentally ill	Subject identification: hospital databases, easier to track youth who will have more heavy system involvement. Subject enrollment: prior to discharge from in-patient treatment, use fewer intermediaries, give out business card, flexibly in interview scheduling and location, pay for/arrange travel logistics (transportation, childcare), provide toll-free/collect call phone numbers. Incentives: at least \$10 for any short interview, gift vouchers. Tracking: local detention facilities and prisons, DMV, former case managers, review of clinical charts to find additional contacts, stop by in person at current address if not responding to letters. Staffing: Use staff not clinically involved with the participant, hire staff with variety of ethnicity, sexual preferences, and socioeconomic status.	Various studies (see article)	
Winship, J. P.	2001	Journal of Children & Poverty	Challenges in evaluating programs serving homeless families	Homeless	Incentives, build partnerships with agencies who may work with the clients you are trying to track (e.g., linkages with transitional housing agencies to track homeless people)	N/A	Article suggests recommendations for tracking.
Wutzke, S. E., Conigrave, K. M., Kogler, B. E., Saunders, J. B., & Hall, W. D.	2000	Drug and Alcohol Review, 19(2), 159–163	Longitudinal research: Methods for maximizing subject follow-up	Substance abusers	Contract information collected: full name, address and phone numbers (both work and home), details for a nominated contact person. Tracking methods: registry of births, deaths and marriages; letters; telephone directories; contact person; medical records; federal electoral commission. Incentives: travel costs, compensation for time; free check of blood pressure, cholesterol, and liver enzymes. Other important study design factors: ongoing contact with participants, persistence and initiative in contacting participants, flexibility in interview timing and location, providing subjects with detailed information about the study and its protection of human subjects.	73% tracked at 10 years	